

Presented by
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Thank you Secretary Takamura, And thank you to the Senate Special Committee for providing a forum for these very timely deliberations, on how we might strengthen and support family caregivers in the critical and irreplaceable roles they play in our society.

The Grotta Foundation was created in 1993 from the sale of the Grotta Center for Senior Care, a non profit nursing home and rehabilitation facility with a 75 year tradition of compassionate care for the elderly. In 1997, through a process of community based needs assessment, and strategic planning the Foundation identified a board definition of caregiving for the elderly as the priority focus of its grantmaking. Caregiving was selected by the Foundation's Board not only because it is an area of need, compellingly supported by this nations emerging demographics, but also because it is a subject that resonated deeply for them on a personal level. For in truth most of us have been, are, or will be caregivers at some point in our own lives.

In creating its own agenda, the Foundation hoped to draw from role models in the philanthropic and corporate worlds. What is discovered however was that for the most part, caregiving for the elderly has yet to take its rightful place on this nation's philanthropic agendas. Some notable exception of course include the Archstone Foundation of California which has most recently issued a three year national funding initiative to "identify new solutions and forge new partnerships that meet the unmet needs of caregivers" the New York City based Brookdale Foundation, which for the past 10 years has funded a National Group Respite Program for Alzheimer's Families, now in 30 States (most recently through a partnership with Grotta in New Jersey) The Jewish Health Care Foundation of Pittsburgh, which looks at caregiving from the perspectives of a women's health, and elder abuse prevention, the United Hospital Fund, with its Families and Health Care Project described earlier today, and the Robert Wood Johnson Foundation's with its faith based volunteer caregiver initiative " Faith in Action." Although this list is I am sure not all inclusive, it is very telling nonetheless when you consider the thousands of foundations that exist in this country.

The corporate response to caregiving predates philanthropy's interest and was initially considered a human resource /employee productivity issue. Major corporation, Travelers, Stride Ride, America Express to name some early leaders, rose to the challenge of the "sandwich generation" by creating a range of employee benefits, EAP caregivers stay on the job. More recently a number of corporations have begun to address the overall human cost of caregiving, and have supported initiatives as a public service to education through the publication and broad dissemination of a practical guide for caregivers. "Aging Parents and Common Sense", and through its Linkages campaign that reaches out to allied health professionals who come into regular contact with caregivers, and who can help connect them to services, "Phizer Inc. has also taken a proactive role, in partnering with the National Council on Aging in a nations Request for Proposals.

"Innovations in Independent Living" to foster original solutions to the challenges faced by care givers.

Given the existing State of the Art, the Grotta Foundation elected to take a broad brush approach towards care giving in its initial funding. As a result it currently is supporting 18 care giving related projects at the local, state and national levels.

Even in its first year the Foundation has already learned much to guide it in the future.

First, it has found that most care givers in this country are not corporate employees, and significant numbers are not the adult children, who have been industry's focus. In fact, many care givers are spouses, who have impairments of their own. What is the impact upon a marriage when one member of a couple must assume the role of caregiver for his or her spouse? Through a Grotta grant, the Main Street Counseling Center of West Orange, New Jersey is looking at this question. It has developed a special outreach to spousal caregivers in senior housing. Through marital counseling and peer support the project helps these older couples work out issues in their marriage that arise because of changing roles and responsibilities inherent in the care giving relationship.

Caregivers can also be grandparents. Today particularly in urban settings, too many of these grandparents find themselves called upon to raise grandchildren, orphaned by the AIDS and drug pandemics. Both the Brookdale Foundation and Hunter College's Brookdale Center on Aging have been leaders in bringing the needs of these at risk families to nation attention. What happens however, when these grandparents are also the care givers of a elderly spouse or parent/ A Gotta grant to the Salvation Army's Grandfamilies Program focuses upon these multigenerational care giving situations offering a panoply of supports to these beleaguered families.

Another emerging demographic is the "aging in " of the developmentally disabled population. These individuals now often survive into their 50's 60's and beyond - their care givers generally are parents whose ages span the 70's to 90's. The question "who will take care of my child when I die" is one of great poignancy and urgency. It poses both a challenge and an opportunity for the aging service and developmental disabilities communities to combine resources, and unite around advocacy positions important to this new dimension of caregiving. Grotta grants to JESpY House of South Orange and the ARC of Union County respectively look at an educational and service coordination approach to helping these elderly caregivers and their adult children plan for their futures.

What do caregivers need from our society to help them maintain their critical roles?

They certainly need respite in all of its permutations, with adult day care at its cornerstone Grotta supports the expansion of social model day care through its partnership with The Brookdale Foundation, and funds a variety of special initiatives within existing programs in New Jersey. A Gotta grant to the Senior Care and Activities Center of Monclair has established "The Club" an adult day care based, early intervention program for early stage

Alzheimer's victims and their caregivers. The Club helps members acclimate to their new and demanding caregiving roles. It has also become a central access point for assessment, education, information, support, and respite.

As we all know caregiving is a 24-hour a day commitment. Planning for respite services must take this into account. A grant to Muhlenberg Adult Day Care Center extends day care to several hours of evening care. This allows for working caregivers to attend support group meetings without worrying about the welfare of their family member. A very innovative program at the Riverdale New York based Hebrew Home for the Aged takes the concept to its next logical level with its Elderserve at Night Program. Here Alzheimer's victims who no longer sleep at night - a frequent symptom of the disease in its middle stage - receive over night care, while their caregivers get a good night sleep.

This nation needs to rethink its commitment to Adult Day Services. At the same time it must explore long term funding mechanisms that makes adult day care an affordable option for the average American.

In 1996 the Grotta Foundation along with five corporate funders supported the National Adult Day Services Association in convening a Blue Ribbon Task Force - its the goal to develop universal standards and guidelines for adult day services. With the standardization of quality care and the publication of the guidelines in 1997, it is now time to look not only to government but also to the managed care industry and corporate America for a financial commitment that allows adult day services to take its rightful place in the continuum of care.

For many caregivers however care begins and remains at home. The availability of affordable, quality homecare is without a doubt the lynchpin of any home based caregiving plan. What is needed is a homecare workforce that is sensitized to the issues facing caregivers and the stresses of the caregiving situation. A Grotta funded project of the Jewish Vocational Service of Metro West recruits mature adults, many of whom have personal experience of caregiving and trains them as certified home health aides. The curriculum specifically addresses the role of the home health aide in relation to the caregiver and reinforces the concept of a care partnership between the caregiver and aide.

In addition several Grotta grants have experimented with creative ways to bring a variety of the therapeutic services offered in the day care setting into the home through caregiver education and training.

The Alzheimer's Association of Northern New Jersey has created "At Home with the ARTS", a 12 week art and music therapy program designed to stimulate mental functioning in Alzheimer's victims. The staff trains family caregivers to carrying out the therapeutic regimen so that they can continue it themselves. Telephone consultation and institutional materials support the caregiver's efforts. Using the same caregiver education principle, Family Services of Morris County, brings occupational and recreational services to mentally intact frail elderly and maintains project community through training and support of the recipient's family or professional caregiver.

Including the caregiver as an integral part of the treatment team has become a repetitive theme of Grotta's funding. This partnership extends from the physician in the hospital to the paid homecare provider in the home.

Earlier to day, Dr. Mary Mittleman of NYU's Alzheimer's Disease Center presented findings of the Center's longitudinal caregiver study. One of the lessons learned over the course of the study has been the hospitalization of a dementia patient poses unique difficulties for caregivers, patients and hospital staff. With a grant from Grotta, the Center has begun work on a handbook at that will educate caregivers to the ins and outs of hospital care for the dementia patient and guide them in how to become an effective advocate within the hospital system. An educational program for hospital staff on how to involve the caregiver in the treatment plan is also in the works with the support of the United Hospital Fund. Ultimately the goal is to establish special hospital based case management teams that will work with families and hospital staff together to improve the hospital experience for these high risk elderly.

Grotta has also directed its funding to developing new resources for caregivers to reduce their isolation and burden.

One area of opportunity often overlooked by planners and policy makers alike is, the wealth of volunteer resources and other supports which faith based communities can offer to ease the plight of caregivers. Through a special Grotta initiative Synagogue HOPE (Help, Opportunities and Programs for Elders) the Foundation is funding pilot programs in local congregations to identify the special role that they can play in enhancing and improving the lives of older adults and their caregivers. As a surrogate extended family, and the locus for mutual support, pastoral outreach, and life cycle celebration, congregations of

all denominations have a unique potential to reach and positively effect the lives of caregivers and the elders in their care. On October 27, 1998, The Grotta Foundation will sponsor a conference "Putting Elders Back on the Congregational Agenda" which will explore these issues and areas of opportunity.

Presenting at the conference will be the Winter Park Health Care Foundation on a pilot caregiver education curriculum created specifically for use by faith based organizations. This model is designed to be volunteer driven and delivered through congregational consortium that would pool their resources and share their experiences.

Older people themselves are an unplumbed resource who are often uniquely qualified to offer caregivers solace and support. A very successful grant to the Alzheimer's Association has provided caregivers with specially trained and supervised senior volunteer companions, who reinforce the project's care coordination services and provide the caregiver with a supportive presence in the home.

Clearly we have only just begun to fully comprehend the many dimensions of caregiving and the implications that these have for our future. This hearing and forum represent a very commendable step in that important direction. However much more work must be done to bring the various sectors of our society together around a commitment that ensures a dignified old age for all Americans. That is why the Grotta Foundation is pleased to join other funders in support of the National Health Council's first Consensus Development Conference on caregiving. This landmark event scheduled for this December will engage government leaders, practitioners and individual caregivers in developing concrete recommendations to integrate family caregiver services within the formal health care system.

Caregivers of the elderly should be viewed as national treasures. Their collective selflessness in providing continuing care for this nation's old and frail has spared our society a staggering financial burden. Without the extraordinary contribution of ordinary everyday people, the quality and security of life that we hold so dear in this country would be dramatically diminished. Elizabeth Cady Stanton once noted that the prosperity of a society can be judged by the way in which it treats its elderly. I suggest that the way we care for those who give care also will define us for future generations.

Thank you.